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ABSTRACT

This study evaluated the augmentative and alternative communication (AAC) assessment and prescriptive practices currently used in various states, through a survey of project directors in all 50 states receiving funding under the Technology Related Assistance for Individuals with Disabilities Act of 1994. The survey instrument assessed directors' knowledge of AAC assessment and prescriptive practices for young children (ages birth to 3) with disabilities and focused on extent of family involvement in existing AAC assistive technology services. Analysis of returned surveys (N=38) are reported for the following areas: service provided during or subsequent to AAC assessment processes; role of families; general factors considered during evaluation; family issues; child characteristics; technology characteristics; and service system characteristics. Analysis indicated that many states consider family issues in the AAC assessment processes, though to a lesser extent than more traditional factors such as child, technology, and service system characteristics. Attached tables detail survey results. Contains 96 references. (DB)

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# Impact of Augmentative and Alternative Communication Devices on Family Functioning: An Examination of Current State Assessment and Prescriptive Practices

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An Examination of States' AAC Assessment and Prescriptive Practices

**Introduction**

Regardless of the theoretical orientation held by professionals working with young children with disabilities, language development is a central concern of intervention efforts directed at both children, families, and caregivers (Bricker & Schiefelbusch, 1990; Dunst, 1981; MacDonald 1989; Manolson, 1992; McDade & Varnedoe, 1987). Federal legislation has influenced the shift toward greater attention being placed on the role of families and caregivers in the language development of young children. P. L. 99-457, the *Education of the Handicapped Act Amendments of 1986*, mandated a family focus on interventions and family participation in planning and implementation of those interventions. Reauthorized under P. L. 102-119, the *Individuals with Disabilities Education Act of 1991* (IDEA), the law reflects a clear intent for professionals to facilitate greater family and caregiver involvement in early intervention service delivery (McGonigel, Kaufmann, & Johnson, 1991; Rosin, Whitehead, Tuchman, Jesian, & Begun, 1993). Similarly, the legislation requires that a multidisciplinary team participate in developing an Individualized Family Service Plan (IFSP) which is responsive to the needs of each family and infant/toddler (Kaiser, 1993; Rosin, Whitehead, Tuchman, Jesian, & Begun, 1993). In early intervention "best practice" (Bailey, 1987; Dunst, 1985; Foster, Berger, & McLean, 1981), the family is considered an integral part of this team, and should be involved in all assessment and intervention stages (Crais, 1991; McGonigel, 1991; Rosin et al., 1993).

Increasingly, in the process of developing IFSPs, young children with disabilities are being provided with assistive technology (Behrmann, Jones, & Wilds, 1989; Parette & VanBiervliet, 1990a; Parette & VanBiervliet, 1991; Parette, Hofmann, & VanBiervliet, 1994). Assistive technology for young children with disabilities is "...any item, piece of equipment, or product system, whether acquired

commercially, off the shelf, modified, or customized, that is used to increase, maintain, or improve the functional capabilities of children with disabilities" [P. L. 102-119, 34 CFR §303.12(d)(1)]. Augmentative and alternative communication (AAC) devices which use synthetic or digitized speech are important assistive technologies used by many young children with disabilities (Church & Glennen, 1992). The goal of any assistive device is to improve the functional capabilities of the child (Behrmann & Lahm, 1983; Church & Glennen, 1992; Developmental Disabilities Program, 1984; Garner & Campbell, 1987), and the provision of AAC devices to young children with disabilities ideally enhances their abilities to functionally communicate. Improvements in functional language capabilities are frequently identified by parents as goals for young children with disabilities during the development of service plans (Behrmann, Jones, & Wilds, 1989; Butler, 1988) with the hope that improved function will facilitate the integration of the child into community settings (Church & Glennen, 1992; Developmental Disabilities Program, 1984; Vanderheiden & Dolan, 1985). When these devices are funded through Part H of IDEA, it is usually subsequent to a comprehensive assessment and evaluation by a team of professionals (McNaughton, 1990; Parette, Hourcade, & VanBiervliet, 1993).

Unfortunately, there is little data currently available to reflect the extent to which states are providing assistive technology to young children with disabilities and their families and funding of devices remains a critical concern for most states (Hayward, Tashjian, Wine, & Curtin, 1992). A range of service providers in the various states maintain data relevant to AAC evaluation and prescriptive processes. For example, the Arkansas Easter Seal Society (1994) conducted 43 AAC evaluations on school-age children during 1993-94, of which 14 were for children ages birth to 2 years, and 29 for children ages 3-18 years. The Nebraska Department of Special Education (1992) reported 54 children ages 0-3 years receiving augmentative

communication and other services during the 1990-91 school year. Contacts made with numerous state agencies in the Midwestern U.S. has revealed that data on expenditures for assistive devices and the number of devices prescribed are not readily available at the state level (Parette, VanBiervliet, & Bradley, 1994). Recent communications with the National Early Childhood Technical Assistance System (NEC•TAS) indicates that data is probably not currently maintained on assistive technology costs due to little demand to spend new Part H monies on these devices, since alternative funding systems (e.g., Medicaid, private insurance) are used (T. Coakley, personal communication, May 25, 1994). However, one state estimated that the average cost of high tech AAC devices, i.e., those which are computerized systems using synthetic or digitized speech (Church & Glennen, 1992), is approximately $2,400 for children ages 0 to 3 years (Sibert, 1992), and can range from $100 to $8,000 in cost. Despite the lack of data regarding the actual number of young children who use AAC devices nationally, communications with various vendors of these devices and agencies involved in AAC assessment and prescription across the country indicate that there is an impetus toward increasing the provision of AAC devices for young children with disabilities (Parette, VanBiervliet, & Bradley, 1994).

Coinciding with the aforementioned impetus are systems change pressures on all states resulting from recent reauthorization of P. L. 100-407 [*The Technology-Related Assistance for Individuals with Disabilities Act of 1994* (P. L. 103-218)]. Under the new legislation, states are required to develop comprehensive statewide programs of technology-related assistance that addresses "the needs of all persons with disabilities, including members of underrepresented populations and members of rural populations; ...without regard to age, type of disability, race, ethnicity or gender of such individuals, or the particular major life activity for which such individuals need the assistance;...without requiring that the assistance be provided

through any particular agency or service delivery system" [§4(4)]. Priority areas in the new language of P. L. 103-218 include (a) development and implementation of strategies designed to overcome barriers regarding access to, provision of, and funding for devices [§102(e)(7)(B)(ii)], (b) technology advocacy for family members in the selection and procurement of assistive devices [§102(e)(7)(B)(iv)], and the development and implementation of strategies to insure timely acquisition and delivery of assistive technology [§102(e)(7)(B)(vi)]. A concomitant issue addressed by P. L. 103-218 is that of underrepresented and underserved populations. Minority persons with disabilities are frequently discriminated against in the human services professions (Blackman, 1994) and it is well-documented that assistive technology service delivery in sparsely populated rural areas is an ongoing issue for service providers (Krajicek & Tompkins, 1993; Parette, Bartlett, & Holder-Brown, in press; Bartlett, Parette, & Holder-Brown, 1994). Absent from the language of P. L. 103-218 reauthorization is any reference to technology impact, though there is a clear mandate to increase the availability of devices to people with disabilities through a variety of funding mechanisms, including Medicaid, private insurance, and P. L. 100-407 projects. Similarly, consumers nationally report a need to obtain evaluative feedback from users of technology on a regular basis coupled with the need to try out technology for at least a month and return it if it fails to meet the needs of the individual (Hayward et al., 1992). Hayword and Elliott (1992), in a national evaluation study involving consumers of disabilities participating in Focus Groups found that state projects funded under P. L. 100-407 should provide (a) more training to parents, employers, and service providers in assistive technology usage; and (b) increase the awareness of technologies available to consumers and professionals. This emphasis is clearly indicated in the recent reauthorization of the legislation, yet little emphasis appears to directed toward evaluating the impact of the technologies provided.

**AAC Impact of Families**

How these various forces affect the *quality* of AAC services provided to young children with disabilities and its impact on family functioning is unknown. Though IDEA mandates that family members play an important role in team decision-making processes (Parette, VanBiervliet, & Bradley, 1994), parents and family members do not always share the same concerns or preferences for AAC devices (Beukelman & Mirenda, 1993). Failure to consider child and family preferences can result in the prescription of an AAC device which the child may not use (Creech, Kissick, Koski, & Musselwhite, 1988).

Since the additional functional capability of children which results from the prescription of AAC devices can dramatically impact family routines and relationships, family values, routines, and resources should be considered in planning for technology services if service plan implementation is to be effective (Brinker, Seifer, & Sameroff, 1994; Gallimore, Weisner, Bernheimer, Guthrie, & Nihira, 1993; Parette, 1994b). In the past decade, there have been suggestions to view the impact of AAC devices across multiple environments, including the home, as opposed to isolated usage of such devices in clinical settings (McNaughton, 1990; Parette, 1994a,b; VanBiervliet, Bradley, & Parette, 1990; Zangari, Lloyd, & Vicker, 1994).

The typical process used to assess family needs involves having parents complete questionnaires that deal with family needs and support networks (Bailey & Simeonsson, 1985; Trivette, Deal, & Dunst, 1986) or team determinations of what devices parents have had success with in the home setting (Parette, Hourcade, & VanBiervliet, 1993). Interestingly, less attention is given to family issues in AAC assessment and prescriptive practices nationally.

Of particular interest to many researchers during the AAC assessment process has been the degree of stress experienced by families of young children with

disabilities (Brinker, Seifer, & Sameroff, 1994; Parette, 1991, 1994a,b). Family stress has been described as an important outcome and mediator of early developmental outcomes (Freidrich, Wilturner, & Cohen, 1985; Hanson & Hanline, 1990). Interestingly, several investigators have alluded to a possible relationship between levels of stress and (a) increased caregiving demands placed on families (Beckman, 1983; Haddad, 1992; Harris, 1988; McNaughton, 1990; Murphy, 1988b), (b) time required for family members to provide intervention services (Brotherson & Goldstein, 1992a), and (c) the introduction of AAC devices (McNaughton, 1990; Parette, 1994b). Several investigators (Brotherson & Oakland, 1994; Brotherson et al., 1994) recently found that families of young children who received assistive devices such as nasogastric tubes must sometimes choose between devices which have an impact on the overall development of their child and quality of life for the entire family. Such choices may also be true for families who must choose between a reasonable quality of life for their families and AAC devices which require changes in routines and increased levels of stress.

It seems reasonable that future AAC assessment and prescriptive strategies consider that devices not only relieve families of some worries about the recipient child and of burdens in the child's care, but often require additions to family routines and restrictions of family activities (Caldwell, Sirvis, Todaro, & Accouloumre, 1991; Condry, 1989; Parette, 1994a,b; Weinstock, 1986). Major changes in family structure resulting from the introduction of AAC devices may severely disrupt family functioning, adversely affecting a family's ability to cope with stress (VanBiervliet, Parette, & Bradley, 1991; Parette, 1994b), and affect the child's development (Murphy, 1988a). Doernberg (1978) noted that the vast majority of services for children with disabilities involve the child's mother as therapist, teacher, trainer, and transporter for the child, leaving little time, money, or energy for the development of *normal interpersonal relationships* for family members.

Should it happen that an AAC device causes severe disruption to the family's normal activities, there may be a breakdown in the family itself (e.g., marital separation or divorce)(Parette, VanBiervliet & Bradley, in press; VanBiervliet, Parette, & Bradley, 1991).

Since many assistive technologies may affect not only the child but the whole family (Murphy, 1988a; Weinstock, 1981), it is important to consider these factors *before* prescribing assistive technologies. Correspondingly, it is important to track the impact on the family following introduction of the device since ongoing resources are expended across time for the child with disabilities and it is important that ethical issues (e.g., family's ability to use a device vs. professional perceptions regarding the most appropriate AAC device for a child and allocation of resources for purchase of the device) guide the decision-making processes. To put the matter more succinctly, family systems are in some ways like physical systems: they have only so much energy to direct in meeting their needs and attaining their desires (VanBiervliet, Parette, & Bradley, 1991). They require from external systems (e.g., community and educational services, assistance from extended family and friendship networks) the kind of input that enables the family to most efficiently and effectively use its energy in its own behalf (Caldwell et al., 1991; Shelton, Jeppson, & Johnson, 1987; Thomas, 1986a, b). This includes the use of technology services. The wrong kind of technology service may not only fail to enhance a family's functioning, but it can actually be a drain on family energy (VanBiervliet, Parette, & Bradley, 1991). This project recognizes that within any system, only a finite amount of energy, or resources exist. Channeling most resources into one component of the system means there may be few resources available for other components and ethics must guide decisions regarding use of available fiscal resources.

Several investigators have previously advocated caution in the use of assistive technologies without an adequate research base. Campbell et al. (1980) emphasized that the indiscriminate use of new technologies may not necessarily result in improved services to children with severe disabilities. Cavalier (1987) suggested that the rush to technologize without an adequate ethical and knowledge base may at times impede a child's progress. Practitioners must be aware of when technology can assist them in meeting identified child needs and when positive outcomes are doubtful, or at best uncertain (Lahm, 1989). Since many assistive technologies may affect not only the child but the whole family, as well as having important ramifications for the resource base of an existing service system, it appears to be very important to consider these factors before prescribing assistive technologies, and to evaluate the impact on the family by the device following its introduction and regular periods thereafter.

With the heightened awareness of limited fiscal resources in today's society, service systems are beginning to more closely examine the manner in which existing resources are expended for children with disabilities (Avorn, 1988; Field, 1990; Hofmann, 1993; Parette, Murdick, & Gartin, 1994; Trachtman, 1990). With the increasing number of AAC devices which are being marketed nationally, it seems reasonable that assessment and prescription of such devices should be scrutinized more closely and that models of AAC assessment be incorporated into the newly emerging family-focused intervention processes which are mandated by P. L. 102-119.

**Purpose and Method**

The purpose of this study was to examine the AAC assessment and prescriptive practices currently exhibited by states. Since it was recognized that there is wide variability across and within states regarding how such practices are typically demonstrated, and that identifying all agencies or groups involved in conducting

AAC assessments and prescribing devices would be an insurmountable task, it was deemed appropriate to target Project Directors for states funded under P. L. 100-407 ($n$ =50), the *Technology-Related Assistance for Individuals with Disabilities Act*. All 50 states currently have received funding under this legislation, though variations exist across states regarding periods of implementation.

An instrument was designed to assess Project Directors' knowledge of AAC assessment and prescriptive practices for young children with disabilities in their respective states, focusing particularly on the extent of family involvement in existing high-tech augmentative and alternative communication (AAC) assistive technology prescription and provision practices for young children with disabilities ages birth to three years in the United States. If Project Directors were unable to address the questions, they were asked to forward it to an appropriate staff person having such information. While it was recognized that this might confound interpretation, the need for information was deemed to be of greater importance than controlling for respondents across states.

High tech AAC assistive technology was defined in the instrument as

> ...any piece of equipment or product system acquired commercially which uses speech that (a) is prescribed for a young child with a disability, (b) is expensive, and (c) requires training on the part of the child, parents, and professionals to program, use, and maintain. Such augmentative and alternative communication devices may be deemed by many individuals to be "high tech". Examples of these devices would include, but not be limited to Liberator™, System 2000™, and Touch Talker™."

Project Directors, or designated project personnel, were also asked to identify (a) their roles, (b) number of children which they had personally been involved in evaluating for AAC devices during the past year, and (c) number of IFSPs which they had personally been involved in developing during the past year. The study

instrument requested information pertaining to services provided to children and family members during or subsequent to the assessment processes, whether or not families participated in AAC assessment processes, factors considered in such processes, family issues which were addressed, and child, technology, and service system characteristics which are considered. Followup telephone calls were made to each recipient who failed to respond following the initial mailing of the instrument along with two additional mailouts during the Spring of 1994.

**Results**

A total of 40 survey instruments were returned (80%) of which 38 of the returned instruments were completed (76%). Of the respondents, 16 (42.1%) were Project Directors, 12 (31.6%) were Speech/Language Pathologists affiliated with the Technology Projects, and 1 (2.6%) was an Early Childhood Special Education Coordinator. A total of 15 (39.5%) respondents identified themselves as having other roles including: Administrator ($n$ = 1); Assistant Project Director ($n$ = 1); Technology Specialists ($n$ = 3); Policy Analyst ($n$ = 3); Parent ($n$ = 1); Occupational Therapists ($n$ = 2); Physical Therapist ($n$ = 1); Speech/Language Pathologist ($n$ = 1); and Special Education Consultant ($n$ = 1). Numerous respondents identified themselves as having several roles (e.g., Project Director/Parent).

Respondents were asked about the number of children ages 0-3 years that they had been involved in evaluating during the past year (Range: 0-35; Mean = 5). Of this group, 18 individuals actually participated in AAC evaluations during the past year (Range: 3-35; Mean =10). Respondents were also asked to identify the number of IFSPs that they had personally been involved in developing during this time frame (Range: 0-40; Mean = 5). Of this group, 10 individuals had actually participated in the development of IFSPs (Range: 5-40; Mean = 19)

**Service provided during or subsequent to AAC assessment processes.** Summary information pertaining to responses on items relating to services

provided by states during or subsequent to AAC assessment processes are presented in Table 1. As can be seen, most states appear to be providing a range of assistive

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Insert Table 1 about here

technology services identified in P. L. 102-119 at least to a limited extent (Range = 40.5-47.4%). Fewer states reported the provision of such services to a great extent (Range = 8.1-35.1%). Of the assistive technology services identified, a substantial number of states (32.4%) indicated that repair of devices was *not* a service provided either during or subsequent to AAC prescription. Respondents who did not know whether such services were being provided in their respective states generally were less than 25% of the total respondent pool (Range = 13.5-24.3). Other services were reported to be provided by several states which included loan of AAC devices from an equipment library and training in use of AAC devices.

**Role of families.** Presented in Table 2 are summary findings related to the reported role of families in AAC evaluation processes prior to IFSP development.

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Insert Table 2 about here

Most states reported that families play a *central role* to either a great or limited extent (68.4%), while 10 respondents (26.3%) did not know whether families participated in such processes.

Respondents were also asked to identify the nature of family involvement in AAC evaluation processes. Of the 38 respondents, 20 (52.6%) reported a range of activities or levels of family involvement. Several states indicated that family involvement varied markedly across facilities in which AAC evaluations were conducted, and it was noted that family members are frequently overwhelmed by technology, do not want to participate in evaluative activities, and need professional assistance in identifying appropriate technology for their children. However, most

states reported that families played primary roles in the needs assessment phase of AAC evaluations, and (a) completed forms, (b) transported their children to and from evaluation sites, and (c) provided input regarding child needs, attitudes, and other critical issue areas. Some states reported that families not only participated in and directed the evaluation processes, but were involved in training sessions after a device was prescribed. Figure 1 illustrates a continuum of involvement along which the identified roles of families were reported to lie.

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Insert Figure 1 about here

**General factors considered during evaluation.** Presented in Table 3 are summary findings of responses related to traditional factors which are considered

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Insert Table 3 about here

during AAC assessment processes. As can be seen, in more than half of the responding states, these factors were considered to a great extent with the exception of funding streams for purchasing devices. Relatively few respondents reported that one or more of these areas were not considered during AAC assessment processes.

**Family issues.** A greater spread in responses was indicated with regard to the consideration of family issues during AAC assessment processes (see Table 4).

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Insert Table 4 about here

Between 5 and 18% of the respondents indicated that specific family issues were not considered, while a substantial number of respondents were uncertain as to whether family factors were considered (Range = 2.8 - 36.8%) in AAC assessment processes.

Open-ended responses to the question "What other family issues are considered?" were also compiled. Respondents identified several other areas that included (a) effect of use of device on siblings and peer groups; (b) willingness and

ability of the family to implement AAC as an early intervention strategy; (c) vocabulary selection, organization, and symbol selection; and (d) relationship between the child's independence in use of the device and "freeing up" family time. Family stress was generally not measured in AAC assessment processes, through several respondents indicated that such measures should be considered prior to the introduction devices. One state respondent indicated that instrumentation to measure stress is currently being developed.

**Child characteristics.** Most respondents reported that child characteristics were considered to a great extent (see Table 5), with the child's ability to use the device, nature and extent of training required for the child to use the device, and

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Insert Table 5 about here

child's past experiences in using AAC devices as being of particular importance. Only two respondents reported that any of these factors were not considered during AAC assessment processes, and a small group of respondents indicated that they did not know whether such factors were considered (Range = 13.5 - 21.6%).

**Technology characteristics.** Presented in Table 6 are summary findings of responses related to technology characteristics which are considered during AAC

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Insert Table 6 about here

assessment processes. As noted, many respondents report consideration of these factors to a great extent, particularly range of devices available, dependability of the device, child/family ability to transport the device, usefulness of the device with other equipment, hands-on opportunities prior to purchase, and degree of comfort in using the device. Extent of protection from theft and damage was a factor considered to a great extent by only two states.

**Service system characteristics.** Presented in Table 7 are summary findings

Insert Table 7 about here

related to service systems factors considered during AAC assessment processes. Three factors were considered to a great extent by 50% or more of the respondents: identification of funding streams available for purchase of devices, service personnel available to support provision of the device, and ability of the service system to provide training to the family and/or child after the provision of the device. Greater variability was reflected in responses related to the extent policies/procedures can be modified to insure acquisition of the device, with six respondents reporting that this factor was not considered in AAC assessment processes and 10 respondents indicating that they did not know whether this factor was considered.

Some respondents provided open-ended information regarding other service system characteristics which were considered. Additional factors reported included (a) ability of future IDEA Part B service providers (schoolage) to deal with the device for transitions; (b) the accessibility and promptness of the service system in responding to service needs; and (c) determination of whether AAC vendor has adequate technical support available to family members (e.g., toll-free technical assistance, loan program when devices are being repaired).

Several respondents reported that no formal instrumentation was used to measure family satisfaction with AAC devices provided to young children with disabilities. Typically, anecdotal reports, family interviews, and follow-up telephone calls were employed to obtain information regarding family satisfaction. Respondents from two states indicated that a family satisfaction instrument was either being revised or in the process of being developed for use with families.

**Discussion**

Examination of the survey findings suggested that family issues are considered by many states in AAC assessment processes, though to a lesser extent than more traditional factors such as child, technology, and service system characteristics. It has been suggested that family factors should be an integral part of AAC assessment processes (Angelo, Jones, & Kokaska, 1993; Jones, Angelo, & Kokaska, 1994; Parette, 1994a; VanBiervliet, Parette, & Bradley, 1991), and such participation is clearly implied in the language of IDEA which emphasizes family involvement in early intervention service planning in the development of IFSPs. While evaluations for AAC devices are frequently conducted outside the IFSP process, the involvement of family members in these evaluations seems necessary given the growing number of investigators who have suggested that stress may result from the introduction of some technologies (Haddad, 1992; Harris, 1988; McNaughton, 1990; Murphy, 1988b; Parette, 1994b). The finding that levels of stress that may result from the provision of AAC devices was typically not a component of AAC assessment processes is problematic. With the increasing emphasis on family-focused early intervention, family issues must be of paramount importance when planning for the introduction of any AAC device. Though instrumentation has yet to be developed which embodies many of the features needed for quality AAC assessment, there is a clear need for new models (VanBiervliet, Parette, & Bradley, 1991; Parette, 1994a,b). Future assessment strategies should be multidimensional and evolve from multiple levels and techniques of information gathering which include the child, family, technology, and service systems factors. Linkages within and among all these factors are incorporated into assessment procedures (VanBiervliet, Parette, & Bradley, 1991; Parette, 1994a,b).

**Use of focus groups.** Clearly, there is a need to investigate effectively the impact and efficacy of AAC device assessment and prescription for young children with disabilities and their families (Brotherson, 1994) to advance the field, inform

policy, and form and strengthen best practices in early intervention programs (Brotherson, 1994; Bruder, 1993; Odom, 1988). Recently, Focus Groups have gained increasing importance to examine the depth and dynamics of interventions used with families of children with disabilities (Bogden & Biklen, 1992; Brotherson, 1994; Glesne & Peshkin, 1992; Langton, 1990; Patton, 1990). It may be that focus group interviewing can provide a holistic analysis of policy and practice in early intervention and increase professional understanding of the diverse issues facing families and agencies serving them. Focus Groups assist in understanding both the anticipated and unanticipated consequences (e.g., increased stress) of early intervention and in interpreting the complexities of multiple families, systems, disciplines, and agencies (Brotherson, 1994), and lead to understanding attitudes, behaviors, and contexts from many points of view (Patton, 1990). Focus Groups are basically group interviews which utilize group interaction to gain information and insights that would not be attainable using quantitative research methodologies (Krueger, 1988; Morgan, 1988), and specifically are designed to elicit multiple perspectives which address questions that inform or assess policy and practice (Brotherson & Goldstein, 1992a).

Specific tasks involved in the use of focus groups for early intervention research have been reported in various research studies (Brotherson, 1994; Brotherson & Goldstein, 1992a; 1992b; Oakland & Brotherson, 1994). Focus Groups can provide a "real life" understanding of the critical concerns, problems, ideas, strategies, and other issues that bear on the issue of AAC impact and families, potentially providing insights into these issues that other traditional data gathering procedures may not yield. Many approaches are used to analyze the qualitative data generated by Focus Groups (Miles & Huberman, 1984; Patton, 1990; Tesch, 1990), which involve a reduction of text from intensive interviews or observations to its essentials. From this information, an organizational AAC assessment scheme

would emerge (Brotherson & Goldstein, 1992b; Brotherson et al., 1994; Johnson & Montague, 1992; Patton, 1990; Tesch, 1990) that could guide professionals and family members and insure that the most appropriate device that considers child, family, technology, and service system characteristics, with an emphasis on family impact.

**Limitations.** The limitations of this preliminary investigation of state AAC assessment and prescriptive practices must be considered before generalizations can be made regarding the data reported. Even though an 80% response rate was obtained from participants in the survey, this is a relatively small sample of the total population of individuals having information regarding AAC assessment and prescriptive practices across states. It would have been most appropriate to have sampled representatives of all agencies and facilities which conduct AAC evaluations in each state. Since information pertaining to specific agencies and groups involved in AAC assessment nationally was not readily accessible, it was felt that P. L. 100-407 Project Directors would have access to some information, or would forward the instrument to appropriate individuals within each state as requested in the cover letter which was sent to them. However, there is great variability across states regarding the involvement of Technology Projects in AAC assessment processes. While some Projects are actively involved in early intervention technology service delivery, other Projects appear to be relatively uninvolved in such processes resulting in the respondents not being particularly interested in participation in the survey. It must also be noted that seven of the state Projects currently funded under P. L. 100-407 only recently received funding and implementation of these state systems of assistive technology service delivery are in their infancy which may have contributed to limitations in the extent of information available to some participants. Support for this limitation was reflected in the fact that three mailings of the instrument and request for participation as well as a follow-up telephone call were made to those states which chose not to participate.

The range of roles reported by respondents was also a limitation which affected the quality of information received. Several Project Directors simply returned uncompleted instruments and reported that AAC evaluations were conducted by numerous agencies statewide and that they could not provide composite information. This was interesting since the design of the survey instrument allowed respondents to simply reply that they "did not know" information regarding a particular response. Several states chose to disseminate survey instruments to all agencies known to conduct AAC evaluations and, while responses from many of these agencies were received, they were not included in data analysis. Examination of these completed instruments did suggest that within those states, considerable variability existed regarding the extent to which variables identified on the survey instrument were considered in AAC assessment processes. The fact that Speech/Language Pathologists, Occupational Therapists, Policy Analyists, and other individuals completed survey forms would suggest that differing training, service perspectives and experiences in AAC assessment probably existed across participants, which may have influenced substantially the quality of information provided.

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Table 1

Responses regarding services that are provided to children during or subsequent to AAC assessment processes

| Service | YES, to a great extent N % | YES, to a limited extent N % | No N % | Don't Know N % |
|---|---|---|---|---|
| **Purchasing and leasing of devices** | 9 (24.3) | 16 (43.2) | 6 (16.2) | 6 (16.2) |
| **Customizing and adaptation of devices** | 9 (24.3) | 20 (54.1) | 3 (8.1) | 5 (13.5) |
| **Repair of devices** | 3 (8.1) | 15 (40.5) | 12 (32.4) | 7 (18.9) |
| **Training in the use of devices for the child** | 12 (32.4) | 18 (48.6) | 2 (5.4) | 5 (13.5) |
| **Training in the use of devices for family members** | 13 (35.1) | 17 (46) | 2 (5.4) | 5 (13.5) |
| **Training in the use of devices for non-family members** | 8 (21.6) | 17 (46) | 3 (8.1) | 9 (24.3) |
| **Coordination of therapies, interventions and services with devices** | 9 (23.7) | 18 (47.4) | 4 (10.5) | 7 (18.4) |

Table 2

Responses regarding whether families play a central role in AAC high tech assistive technology evaluation processes prior to developing IFSPs

| | YES, to a great extent | | YES, to a limited extent | | No | | Don't Know | |
|---|---|---|---|---|---|---|---|---|
| **Question** | N | % | N | % | N | % | N | % |
| **Do families play a central role?** | 14 | (36.8) | 12 | (31.6) | 2 | (5.2) | 10 | (26.3) |

Table 3

Responses regarding factors are considered during AAC "high tech" assistive technology assessment processes

| Factor | YES, to a great extent N % | YES, to a limited extent N % | No N % | Don't Know N % |
|---|---|---|---|---|
| **How the device improves functional performance of the child without compromising other areas of performance** | 26 (68.4) | 6 (15.8) | 0 (0) | 6 (15.8) |
| **The reliability of device** | 24 (63.2) | 6 (15.8) | 0 (0) | 8 (21) |
| **The ease with which device can be used and operated** | 28 (73.7) | 4 (10.5) | 0 (0) | 6 (15.8) |
| **The reasonableness of the service and repair costs for device** | 16 (57.1) | 12 (42.9) | 0 (0) | 0 (0) |
| **Identification of funding streams for purchasing device** | 18 (47.4) | 16 (42.1) | 0 (0) | 4 (10.5) |
| **Identification of training needs that would enable the child to use device** | 22 (57.9) | 10 (26.3) | 1 (2.6) | 5 (13.2) |
| **Identification of training needs that would enable family members to use device** | 20 (52.6) | 10 (26.3) | 2 (5.3) | 6 (15.8) |
| **Identification of training needs that would enable paraprofessionals to use device** | 14 (36.8) | 14 (36.8) | 1 (2.6) | 9 (23.7) |
| **Identification of training needs that would enable professionals to use device** | 16 (42.1) | 13 (34.2) | 2 (5.3) | 7 (18.4) |

Table 4

Responses regarding family issues are considered in AAC "high tech" assistive technology assessment processes

| Factor | YES, to a great extent N % | YES, to a limited extent N % | No N % | Don't Know N % |
|---|---|---|---|---|
| **Extent of changes in family routine/s affected by use or maintenance of device** | 15 (39.5) | 11 (28.9) | 2 (5.3) | 10 (26.3) |
| **Extent family members must assume additional child care responsibilities in home by child's use or maintenance of device** | 6 (15.8) | 11 (28.9) | 7 (18.4) | 14 (36.8) |
| **Extent of restrictions in family activities resulting through child's use or maintenance of device** | 2 (5.3) | 16 (42.1) | 7 (18.4) | 13 (34.2) |
| **Extent of modifications in home environment required for use or maintenance of device** | 9 (23.7) | 14 (36.8) | 4 (10.5) | 11 (28.9) |
| **Ability of family to cope with stress** | 7 (18.4) | 14 (36.8) | 6 (15.8) | 11 (28.9) |
| **Extent to which family needs are balanced with existing resources** | 8 (21.1) | 14 (36.8) | 6 (15.8) | 10 (26.3) |
| **Financial resources required of family for child to use and maintain device** | 9 (23.7) | 16 (42.1) | 4 (10.5) | 9 (23.7) |
| **Extent of support personnel and community resources available to family over time for training and maintenance of the device** | 12 (32.4) | 12 (32.4) | 3 (8.1) | 10 (27) |
| **Family preferences for an AAC device** | 16 (44.4) | 14 (38.8) | 0 (0) | 6 (2.8) |

Table 5

Responses regarding child characteristics considered in AAC "high tech" assistive technology assessment processes

| Factor | YES, to a great extent N % | YES, to a limited extent N % | No N % | Don't Know N % |
|---|---|---|---|---|
| **Physical ability to use the device** | 30 (81.1) | 1 (2.6) | 0 (0) | 6 (16.2) |
| **Cognitive functioning level** | 23 (62.1) | 9 (24.3) | 0 (0) | 5 (13.5) |
| **Degree of integration into community activities (including service program) that will be achieved through use of the device** | 18 (48.6) | 14 (37.8) | 0 (0) | 5 (13.5) |
| **Nature and extent of training required for the child to use the device** | 23 (62.2) | 8 (21.6) | 1 (2.7) | 5 (13.5) |
| **Child's past experiences in using AAC devices** | 23 (62.2) | 7 (18.9) | 1 (2.7) | 6 (16.2) |
| **Child preferences for an AAC device** | 17 (45.9) | 12 (32.4) | 0 (0) | 8 (21.6) |

Table 6

Responses regarding technology characteristics considered in AAC "high tech" assistive technology assessment processes

| Factor | YES, to a great extent N % | YES, to a limited extent N % | No N % | Don't Know N % |
|---|---|---|---|---|
| **Range of devices available** | 26 (68.4) | 5 (13.2) | 0 (0) | 2 (5.3) |
| **Real cost of devices (includes *hidden* costs, such as repair, maintenance, etc.)** | 16 (42.1) | 11 (28.9) | 3 (7.8) | 8 (21.1) |
| **Dependability of device** | 25 (65.8) | 6 (15.8) | 1 (2.6) | 6 (15.8) |
| **Child/Family ability to transport/move device across environmental settings** | 22 (57.9) | 7 (18.4) | 1 (2.6) | 8 (21.1) |
| **Lifespan of device** | 13 (28.9) | 16 (36.8) | 2 (2.6) | 7 (7.9) |
| **Usefulness of device with other equipment (e.g., computers, software)** | 18 (47.4) | 13 (34.2) | 1 (2.6) | 6 (15.8) |
| **Hands-on opportunities to use device prior to purchase** | 23 (60.5) | 7 (18.4) | 1 (2.6) | 7 (18.4) |
| **Maintenance requirements** | 11 (28.9) | 18 (47.4) | 1 (2.6) | 8 (21.1) |
| **Extent of protection from theft and damage** | 2 (5.3) | 22 (57.9) | 5 (13.2) | 9 (23.7) |
| **Safety features of device (i.e., will the child/family be safe from injury when using the device)** | 13 (35.1) | 12 (32.4) | 3 (8.1) | 9 (24.3) |
| **Degree of comfort child/family experience in using device (i.e., does it cause fatigue, undue physical exertion, etc.)** | 21 (55.3) | 10 (26.3) | 1 (2.6) | 6 (15.8) |
| **Ease of repair** | 11 (29.7) | 18 (48.6) | 1 (2.7) | 7 (18.9) |

Table 7

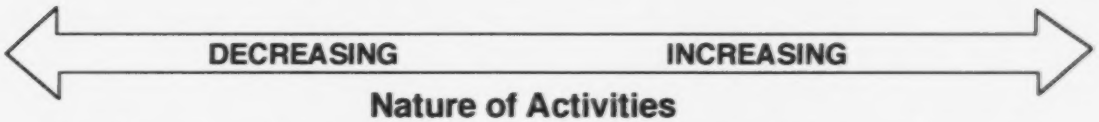
Responses regarding service system characteristics considered in AAC "high tech" assistive technology assessment processes

| Factor | YES, to a great extent N % | YES, to a limited extent N % | No N % | Don't Know N % |
|---|---|---|---|---|
| **Funding streams available for purchase of device** | 21 (55.3) | 11 (28.9) | 1 (2.6) | 5 (13.2) |
| **Service personnel available to support the provision of device to the child and family** | 20 (52.6) | 11 (28.9) | 1 (2.6) | 6 (15.8) |
| **Extent policies/procedures can be modified to insure acquisition of device** | 10 (26.3) | 12 (31.6) | 6 (15.8) | 10 (26.3) |
| **Ability of service system to follow-up with the family and child within 6 months of provision of device** | 16 (42.1) | 11 (28.9) | 2 (5.3) | 9 (23.7) |
| **Ability of service system to provide training to the family and/or child after the provision of device** | 20 (52.6) | 10 (26.3) | 1 (2.6) | 7 (18.4) |
| **Ability of personnel involved in prescribing AAC devices to follow-up on IFSP implementation after provision of device** | 14 (36.8) | 13 (34.2) | 2 (5.3) | 9 (23.7) |
| **Ability of service system to measure family satisfaction with device** | 5 (13.2) | 17 (44.7) | 7 (18.4) | 9 (23.7) |

## Figure Caption

*Figure 1.* Summary of continuum of family AAC evaulation roles identified by respondents.

## Continuum of Family Roles in AAC Assessment Processes




**Nature of Activities**

| *Passive Recipients of Services* | *Active and Ongoing Involvement* |
|---|---|
| • Transportation | • Pursuing Referrals |
| • Completing Forms | • Evaluation Conference Participation |
| • Providing Information | • Directing Evaluation Strategies |
| • Observation of Professional-Identified Strategies | • Providing Device Prescription Evaluation Information |
| • No Involvement in Processes | • Participation in Training |